

My name is Barbara. I am 58 years old and a widow after watching my husband of 30 years die slowly.

Alan was diagnosed when he was 50 years old with Parkinsons Disease. Six years later, he was diagnosed with Parkinsons Disease related Dementia and I had to put him in a home as his mental state deteriorated so badly, I couldnt care for him at home anymore.

The next two years were horrible: emotionally, financially, physically and mentally for me and our two daughters. My girls asked permission not to see Alan anymore as he was rapidly turning into someone they didnt know. They wanted to remember their daddy and who he was, not this person in his shell.

During those two years, there were many trips to the hospital, medication changes, emergency calls at work, unending paperwork, financial despair, emotional crippling and a never ending feeling of despair because I couldnt carry out his one wish for death with dignity. He was now wheelchair and bedbound in 2011, just seven short years after he was diagnosed.

When he was first diagnosed, we talked every day about his disease and its outcome.

He knew it would be bad and all he wanted was death with dignity. He didnt want to be in diapers, hand fed eating mush for food, and not knowing who he was or where he was. It frightened him.

In November 2011, I asked them to stop moving him from bed to wheelchair as you could see the pain it caused just moving him. PD causes rigidity and the movement was excruciating. It was November 2011 and he was 58 and completely bedbound. He no longer knew who I was. I went to see him every day to be sure he was being treated well and at this time, Hospice came into the picture. There was someone checking on him all the time, so I could take a day off as I was emotionally exhausted and suffering severe depression. I would feel guilty on the days I didnt go to see him and that just intensified my depression.

By December, he was covered with bedsores, not eating at all as his swallowing mechanism had gone either due to the PD or the dementia. By early January, he was sleeping 23 hours a day and was on morphine for pain. He weighed 86 pounds.

In late January, they called me and said he was running a high fever and that was the first indication that death was near.

I went to the home and stayed with him for the next 36 hours until he took his last breath on Saturday, January 28th, 2012 at 2:00 pm at the age of 58.

His wish of death with dignity never occurred. I am asking, no BEGGING, for our laws to change. No family should have to go through an experience such as this.

Unfortunately, I will be in this situation again as my 30 year old daughter has Cystic Fibrosis with an average life expectancy of 38. Although the physical experience will be different for her, the emotional is the same. She wants death with dignity and I again

will be in a position to do nothing for her to honor that wish. BUT I will be living through another horrible death which you could help prevent by changing laws and allowing families to let their loved ones go peacefully.

As a footnote, I would like to mention that Alan's brain was donated to science, per his wishes, for research. Anything that could help another family not have to travel this dark path helps make his absence a little easier but it still doesn't solve the issue of Death with Dignity. Only you can do that!

Thank you

Barbara Gode Wiles